

## Talking with Children



Books are a good way to help children understand

### Advice for Parents

By Eva Guralnick

It's difficult enough to be faced with a brain tumor, but parents face an extra challenge when they must help their children understand and face the news as well. They wonder how much their children can comprehend, what to say, and the best way to say it. Above all, they want their children to continue to thrive and do well despite the major changes that may lie ahead for the entire family.

We asked two experts for advice on how parents can best approach their children about a brain tumor diagnosis. Stacy Kramer, LCSW is the Children's Services Program Coordinator for Cancer Care, a national nonprofit organization that provides free, professional support services to anyone affected by cancer. The

agency's Cancer Care for Kids® program was designed specifically to work with the children of parents diagnosed with cancer.

Erika Maslan, LMFT and a PhD candidate, works with The Wellness Community, where she has facilitated a brain tumor support group for nearly 20 years. She also works regularly with children of parents who have cancer, and is a faculty member at UC Berkeley, teaching in the Extension Division. Her specialization is Loss and Grief in Childhood and Adolescence.

The question is not *if* you should tell your children, but *how*. "Some people ask me if it would be better not to tell their children anything about what's going on," said Kramer. "I explain that kids know more than you think and will know that something's wrong. They will often create their own story about what's going on—and a lot of times their story is worse than the real situation. You're better off explaining what's truly going on."

**Keep your explanation age appropriate.** Children will have different abilities to understand the news depending on their age. A very simple explanation is fine for a small child, while a teen will probably want and need more specific information. If necessary, parents can rehearse with a friend or a clinician until they feel comfortable with what they're going to say. Answer the questions, keep it simple, wait for the next question and listen carefully to what is being asked. There's no need to provide too much information at once, as it will only overwhelm the child or teen.

"With a 4-year-old you should use simple terms and perhaps look for a book you can read together that deals with a family member or loved one who is seriously ill or hospitalized," said Maslan. "Say that Mom or Dad has a spot or bump in their head that doesn't belong there, and explain what is going to be done about it in words they can understand." A 17-year-old can cope with a more detailed explanation about the diagnosis and treatment.

Regardless of their age, all children should be reassured that they did nothing to cause the tumor. "It's a common fear," said Kramer. "Not only little children but even teens can engage in a kind of magical thinking in which they

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Despite this experience, they can come out the other end being really healthy children and adults.

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worry that something they did or said caused the tumor. They need to hear from their parents that it's not anyone's fault."

**It's okay to show emotion.** Many parents worry that they will cry in front of their children when they tell them about the diagnosis. Kramer encourages them to pick a quiet time at home to have the conversation in case they feel teary. "I also tell them that it's okay to cry sometimes in front of your children," she said. "You're modeling that emotions are okay." Maslan concurred. "Of course feelings will come into play," she said. "If you feel really sad and you cry, you're showing your children that feelings are part of this journey, sadness can be appropriate, and you don't have to hide your emotions."

**Be ready for questions about death.** Another significant concern for parents is that their children will ask if Mom or Dad is going to die. "Our gut instinct in moments like that is to lie and say absolutely not," said Kramer. "But the reality is that you want to be honest and say 'I don't want

to die. Mommy's going to the doctor and getting very strong medicine and following all the doctor's instructions, because I want to do my best to beat this.' Trust between parent and child is very important."

**Prepare your children for what's ahead.** The known is less scary than the unknown, so let your children know ahead of time that after surgery, Mom's head will be shaved, or that Dad may have a scar the next time they see him.

**Leave the door open for future questions and conversations.** "No matter how old your children are, you should let them know that if they're confused or something doesn't make sense, they should just ask," said Maslan. "Let them know they can ask questions and talk about their feelings."

**Reassure children that their needs will still be met.** Let children know that they can still depend on you and others to take care of them, pick them up from school, tuck them in, and all the other things that happen daily. "Children and teens need consistency and parents should try to maintain



Children need information and reassurance.

as many of their normal routines as possible given the situation," said Kramer. As part of this, parents should also avoid letting an older child become a substitute parent for the younger ones.

**Expect some backsliding.** "Some form of regression in behavior is perfectly normal and to be expected," said Maslan. "Parents should just try to be patient with it, as long as it's not behavior that is self-destructive or hurts others. With small children it might mean that they suddenly can't function at developmental levels they've mastered earlier. Toilet training in particular might become an issue again." Older children may have problems with schoolwork or friends, feeling isolated and "different." However, more extreme issues such as noticeable depression, excessive or destructive anger, or withdrawal and isolation are warning signs and do require professional attention.

**Remember that children can grow and learn from adversity.** "Parents worry that their having cancer will hurt their child," said Kramer, "but many of the people who grow up to be good, caring adults have had something like this in their childhood. These kids can become very empathetic and sensitive, and grow up to be our best helping professionals. That's a positive outcome parents don't always think about. A lot of doctors and scientists grew up wanting to cure cancer because someone in their family had it. Despite this experience, they can come out the other end being really healthy children and adults."

## Online Resources for Parents Coping with Cancer

- >> **CancerCare** offers information for patients and loved ones. A program called CancerCare for Kids® offers specialized information for parents. [www.cancercare.org](http://www.cancercare.org)
- >> **The Wellness Community**, a nonprofit agency, provides free support, education and hope to people with cancer and their loved ones. [www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)
- >> **National Brain Tumor Foundation** offers the book *My Name Is Buddy: A Story for Children About Brain Tumors* free of charge. [www.brainumor.org](http://www.brainumor.org) or 800.934.2873
- >> **The National Cancer Institute's website** offers Taking Time: Support for People with Cancer, and a brochure titled "When Your Parent Has Cancer: A Guide for Teens" (Publication No. 05-5734). [www.cancer.gov/cancertopics/takingtime](http://www.cancer.gov/cancertopics/takingtime)
- >> **SuperSibs** offers children support when a sibling has cancer. [www.supersibs.org](http://www.supersibs.org)
- >> **Kids Connected** provides friendship, understanding, education, and support for children who have a parent with cancer. [www.kidsconnected.org](http://www.kidsconnected.org)
- >> **American Cancer Society** offers information for patients, friends and family, including "Helping Children When a Family Member Has Cancer." [www.cancer.org](http://www.cancer.org)
- >> **National Students of Ailing Mothers and Fathers Support Network** supports college students with an ailing or deceased loved one. [www.studentsofamf.org](http://www.studentsofamf.org)

# Announcements

## Support for Returning to Work

Are you a brain tumor survivor thinking about going back to work? Check out NBTF's pamphlet *Returning to Work: Is it Right for You?* for information that will help guide you through this decision. It offers helpful information both on workplace issues and disability coverage. Available at [www.braintumor.org](http://www.braintumor.org) or call 800.934.2873 for your free copy.

## Brain Metastases Explained

Patients and caregivers coping with a brain tumor caused by cancer from elsewhere in the body will find *Understanding Brain Metastases* a great resource. NBTF has recently updated this much-requested brochure. To obtain a free copy, visit [www.braintumor.org](http://www.braintumor.org) or call 800.934.2873.

## Hot off the Press! New Books on Brain Tumors

*Curveball: When Life Throws You a Brain Tumor*, written by Liz Holzemer, a brain tumor survivor and founder of the Meningioma Mommas, recounts her experiences after being diagnosed with a baseball-size meningioma. Holzemer overcame many obstacles on her long road to recovery. *How to Get the Health Care You Want – A Savvy Consumer's Guide to Navigating the Health Care System* by Laura L. Casey offers advice on how to communicate with your health care team, create long-term, mutually beneficial care relationships, and tailor your health care to your personal values, standards and budget. Casey offers her experience as a patient, patient advocate, and professional.

## Support Groups Are Only a Click Away

Looking for a support group in your area? Check out the newly updated state-by-state listing of brain tumor support groups on the NBTF website at [www.braintumor.org](http://www.braintumor.org) to find the one nearest you. There are over 180 groups listed, and if you don't see one in your area, we're happy to help you locate other support resources. Call our office for more information.

Do you facilitate a support group for brain tumor patients and their loved ones? Please call our office at 800.934.2873 and tell us about your group so that we can add it to the website.

## Swing for the Cure

Let hope live! The 7th Annual Andrew Christian Bryce Foundation Swing for the Cure Golf Classic will be held July 16 at the Troy Country Club in Troy, New York. Each year, organizer Kyle Elizabeth Bryce holds this golfing event to honor the memory of her son, Andrew Bryce, and raises funds for innovative pediatric cancer research. In past years, the Foundation has supported a total of \$150,000 for the NBTF Andrew Christian Bryce Pediatric Research Grant. We encourage everyone in the area to attend this fun and important day. For more information and to register please call 518.273.8020 or visit [www.lethopelive.org](http://www.lethopelive.org).

## clinical trials

For more details on these trials, please visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and enter the trial ID # or call NBTF at 800.934.2873 to request a copy of the study details.

### Effect of NovoTTF-100A in Recurrent GBM

Sponsored by NovoCure Ltd.

Trial #: NCT00379470

Contact: Eilon D Kirson, MD-PhD at [eilon@novo-cure.com](mailto:eilon@novo-cure.com) or Martin Kleber at 646.227.2269.

### Viral Therapy in Treating Patients with Recurrent Glioblastoma Multiforme

Sponsored by Mayo Clinic and National Cancer Institute

Trial #: NCT00390299

Contact: Clinical Trials Office - Mayo Clinic Cancer Center at 507.538.7623

### Phase I/II Pazopanib Plus Lapatinib for Relapsed Malignant Glioma

Sponsored by M.D. Anderson Cancer Center and GlaxoSmithKline

Trial #: NCT00412711

Contact: Morris D. Groves, MD at 713.792.6600

### Intracerebral Clysis in Treating Patients with Recurrent Primary Brain Tumors

Sponsored by Columbia University and Herbert Irving Comprehensive Cancer Center

Trial #: NCT00452959

Contact: Jeffrey Bruce, MD at 212.305.7346 or [jnb2@columbia.edu](mailto:jnb2@columbia.edu)

### Multiple Dose Study of MPC-6827 in Subjects with Refractory Brain Metastases

Sponsored by Myriad Pharmaceuticals

Trial #: NCT00393965

Contact: Stirlynn Mike at 888.459.4888 or [smike@myriad.com](mailto:smike@myriad.com), or Chris Clark, BS at 888.459.4888 or [cclark@myriad.com](mailto:cclark@myriad.com)

### Cilengitide in Treating Patients Who Are Undergoing Surgery for Recurrent or Progressive Glioblastoma Multiforme

Sponsored by North American Brain Tumor Consortium and National Cancer Institute

Trial #: NCT00112866

Contact: NCI Clinical Trials Referral Office at 888.NCI.1937 or the Clinical Trials Office - M.D. Anderson Cancer Center at 713.792.3245

### RTA 744 in Treating Patients with Recurrent or Refractory Anaplastic Astrocytoma, Anaplastic Oligodendroglioma, Anaplastic Mixed Oligoastrocytoma, Glioblastoma Multiforme, or Gliosarcoma

Sponsored by Jonsson Comprehensive Cancer Center and National Cancer Institute

Trial #: NCT00346203

Contact: Clinical Trials Office - Jonsson Comprehensive Cancer Center at 888.798.0719

### Pemetrexed Disodium in Treating Patients with Recurrent Malignant Gliomas, Primary CNS Lymphoma, or Brain Metastases

Sponsored by Robert H. Lurie Cancer Center and National Cancer Institute

Trial #: NCT00276783

Contact: Clinical Trials Office - Robert H. Lurie Comprehensive Cancer at 312.695.1301 or [cancer@northwestern.edu](mailto:cancer@northwestern.edu)

# Research Report: Genes and Brain Tumors

By Eva Guralnick

*Melissa Bondy, PhD, Professor of Epidemiology at M.D. Anderson Cancer Center at the University of Texas in Houston, is leading a new study that seeks to determine a hereditary connection for gliomas. NBTF, along with the National Cancer Institute, is proud to provide funding for this important study. Dr. Bondy spoke with Search recently about the goals and hopes for her research.*

## What is the Gliogene Study?

The Gliogene Study is an international consortium of brain tumor researchers in the United States, the United Kingdom, Sweden, Denmark and Israel. We are hoping to learn more about possible genes related to brain tumors, and then identify a genetic link among family members of brain tumor patients. Identifying a genetic link may provide information about the disease that one day we hope will lead to improved treatment and preventive strategies.

## Who is taking part in the Gliogene Study?

We're recruiting families with two or more biologically related members who have been diagnosed with a primary brain tumor that is a glioma. It can be any type of glioma, including astrocytoma, oligodendroglioma or glioblastoma multiforme. Participating families take part in a 45-minute research interview and risk questionnaire over the phone or in person, and then some members of the family are providing small blood samples to help identify the possible genes related to the development of brain tumors. The families are being referred from many different sources, including the internet, word of mouth, and through all the collaborating institutions.

## How large is the Gliogene Study?

The Gliogene Study is the largest study ever to be conducted on families in which more than one member has a glioma. Researchers aim to screen more than 16,000 individuals worldwide through 15 institutions during the five-year study. Brain tumors are so rare that no one institution sees enough cases to be able to conduct large-scale studies, so we couldn't do this type of research if we hadn't developed this study as a collaborative, international process. My facility, for example, would only get about 40 families per year who would be eligible for the study. We already had a network established thanks to the Brain Tumor Epidemiology Consortium (BTEC), which is supported by NBTF. This is an open scientific forum organized to foster the development of multi-center, international and inter-disciplinary collaborations that will lead to a better understanding of the etiology, outcomes, and prevention of brain tumors.

## How frequently are brain tumors caused by hereditary factors?

So far, researchers have been able to find a hereditary link in approximately 5 percent of brain tumors, so it's very rare. However, we think that with a study of this size, we may be able to identify more brain tumors that have a hereditary link.



Melissa Bondy, PhD

F. Carter Smith

## What impact do you hope your research will have?

If we can identify the genes responsible, it could open up possibilities of gene therapy and other types of targeted therapies. We could also identify who might be appropriate for more screening, the way we do with a disease such as colon cancer. In addition to giving us a better understanding of the genetics of familial brain tumors, we think that the genes identified from our participating families will be extremely important for all glioma patients. What we learn here will also be a foundation for future research.

## Why did you decide to focus on brain tumors?

I've devoted my whole career to brain tumors and I have a passion to understand something we know very little about. With this study in particular, I think for the first time we've been able to put a study together that will hopefully identify large numbers of people so we can have sufficient sample size, which is always a challenge in brain tumor research. It's also exciting to work with a group of people who are so energetic and also have the passion to be able to learn more about the disease. We really appreciate the willingness of these families to participate, and we hope we'll be able to offer them some new information when the study is complete.

For more information, visit [www.gliogene.org](http://www.gliogene.org).

# Ask the Health Professional

By Mary Lovely, RN, PhD

## Getting a Second Opinion

### Question:

My family and friends say that I need to get a second opinion. What are the benefits of getting a second opinion and what will I need to get a second opinion?

### Answer:

Getting a second opinion means asking another physician to review your case. It can confirm an initial diagnosis and/or be used to compare suggested courses of treatment. Some people find it difficult to seek a second opinion for fear of offending their physician. Patients have a right to a second opinion and that is now acknowledged by most health care professionals.

Second opinions involve a review of pathology reports, laboratory tests, medical records and notes from the doctor who diagnosed the illness. Many medical centers offer the services of a tumor board to discuss difficult cases. A tumor board is a multidisciplinary group of health care providers involved in the treatment and diagnosis of central nervous system tumors. The board may include neurosurgeons, neuro-oncologists, radiation oncologists, pathologists and other medical professionals. The tumor board reviews the patient's MRI films and clinical and pathological information, discusses treatment options and makes a group recommendation regarding treatment.

The doctor reviewing the case for the second opinion will need copies of all scans, diagnostic tests, lab and pathology reports and all records regarding the condition. Ask his or her office to specify exactly what information must be provided to properly evaluate your case. Request copies of your chart and MRIs from the staff at your doctor's office.

Second opinions can sometimes be confusing because doctors may have different treatment approaches, all within the National Comprehensive Cancer Network's published standards for care. Sometimes people obtain a third opinion to help them decide how to proceed. Ultimately, the patient and family will have to decide which doctor and treatment will fit their needs.

For more information, please see NBTF's fact sheet "How and Why to Get a Second Opinion."

Mary Lovely, RN, PhD, Medical Information Specialist (made possible with financial support from the Tim & Tom Gullikson Foundation), is available to answer your questions concerning brain tumors. Contact her by visiting the Ask The Health Professional section at [www.braintumor.org](http://www.braintumor.org), or by calling 800.934.2873.

The general medical information provided in this column is not a substitute for your doctor's medical advice. Consult your physician about your individual medical treatment.

## RACING AHEAD® Wins Again!

All across the country, brain tumor patients, their friends and families are participating in athletic events of their choosing to raise money for National Brain Tumor Foundation programs. Here are some great success stories.

### The DisneyWorld Marathon in Orlando, Florida

The DisneyWorld Marathon, held January 7, was a special way for Michele McColgan to celebrate her love for her mother. "My mother taught me so much, and I miss her," said Michele. "It is important for me to help others facing brain cancer. My goal was to raise \$1,000 for NBTF, and slow down a bit when running through Fantasy Land, and I succeeded at both!"



Sarah Trejo

### The Los Angeles Marathon

This is the fourth year for an LA Marathon Racing Ahead Team, but for the first time, our Team Captain works at NBTF! "The survivors, loved ones and friends of people who have faced brain tumors have left me in awe," said Sarah Trejo, our Patient Services Program Manager. "I wanted to show them my support." The NBTF team of Sarah Trejo, Thomas Westfall, Kimberley Ferrari, True

Pawluk, Michael Silva and Vicki Basil raised nearly \$6,000 when they ran on March 4!

### The Chevron Houston Marathon

"Each of us takes the best path we can find in search of a balance and reason," said Cara Collier, "and that is why I ran in the Chevron Houston Marathon on January 14. Remembering how Christopher spent hours in the Brain and Spine Center, I learned a new perspective on life! Each day, each moment is important. Pushing myself to prove this, and raise over \$3,000 for NBTF, is the best way I can think of to help others."

### The Long Branch Marathon – Long Branch, NJ

"Life is rarely simple," said Tim Ragan. "My first seizure was in 2003, while in school. My second surgery was in 2006, just as pre-med classes were wrapping. I was diagnosed with a Grade III oligodendroglioma. Running became a passion for me. My survival should not be seen as an 'exception'. It should be the rule. I raised over \$15,000 for NBTF when I ran on April 29 and plan to continue!"

For more information on how to organize your own Racing Ahead® event, visit [www.braintumor.org](http://www.braintumor.org) and click on Racing Ahead®, email us at [racingahead@braintumor.org](mailto:racingahead@braintumor.org), or call 800.934.2873.



## *A World Without Brain Tumors...*

May 2007

Dear Friends,

In August 2004, I was diagnosed with an oligoastrocytoma. Ironically, it was at a good friend's bachelor party in Las Vegas that I first noticed symptoms of the tumor, a tingling sensation in my left arm, left foot, and across the bridge of my nose. I was only twenty-five.

Needless to say, being diagnosed with a brain tumor changed my life. I had always been an active person, but after undergoing two surgeries, radiation, and chemotherapy, I had to seriously cut back on my activities. I learned the important lesson of adjusting and adapting to my ever-changing situation.

My family, friends and co-workers were a tremendous source of support. Prior to my diagnosis, I knew nothing about brain tumors. When my family and I reached out to the National Brain Tumor Foundation, we received information about treatment options, symptom management, and support groups. The information helped my whole family prepare for the difficult months following my diagnosis.

In volunteering with NBTF, I have met a community of people who, like me, have been touched by brain tumors. Knowing that I am not alone in this experience has made a world of difference. I know I am part of a community.

Please consider including NBTF in your estate plan. A planned gift (e.g., a bequest) is drawn from your assets as opposed to your income, and represents additional ability you have to support the brain tumor cause.

Today, as I write this letter to you, I am filled with optimism and hope for the future. With on-going research efforts funded by NBTF and others, I envision a world where a cure would be at hand. I envision a world without brain tumors.

Sincerely,

Adam Clar  
NBTF Volunteer

### **Please include NBTF in your estate plan!**

Complete and return the enclosed Reply Form so that NBTF can update you with new developments in the estate-planning field.

Your information will be kept private and confidential.

## Angel Adventure® Walk and Community Day

JOIN US!  
2007 Calendar

**Denver, CO**  
June 9

**Portland, OR**  
September 8

**San Diego, CA**  
September 29

**New!** **Washington, DC**  
October 6

**Phoenix, AZ**  
October 14

**Orange County, CA**  
October 20

**Dallas-Ft. Worth, TX**  
November 3

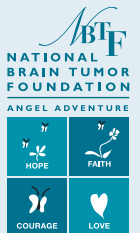
Come out and support NBTF's  
Angel Adventure® fundraising walk  
and community day.



Join Angel Adventure® Walk and Community Day, a celebration day to meet those who have been touched by brain tumors, celebrate life and honor the memory of those no longer with us. Participate as an individual or part of a team and raise money for brain tumor research and patient services. Organize a team of family members, friends and office co-workers! It's fun and rewarding!

### Register Online!

Go to [www.braintumor.org](http://www.braintumor.org), click "Angel Adventure® Walk" or call toll-free 1.866.455.3214. You can build your own personal fundraising web page and send email messages to your family and friends.



## Legacy Corner

For more information about this new law, please contact your professional legal or financial adviser.

### IRA Charitable Rollover

**New law encourages charitable gifts from IRA funds**

A new law was passed on August 17, 2006, allowing donors to make charitable gifts from their IRA funds without recognizing such IRA distributions as taxable income.

Typically, IRA withdrawals are taxed as income at time of distribution. The new law applies to donors aged 70-1/2 and over and to gifts made in 2006 and 2007 only. Up to \$100,000 may be given in this manner in each tax year.

# Successful fundraisers support NBTf

## Celebrating Life! A Tribute to Rich Krukowski

### Pennsylvania

Dozens of family and friends of the Krukowski-McGovern circle turned out to support Celebrating Life!, a golf benefit in memory of Rich Krukowski. The event, organized by Rich's wife, Mary, and sons, Robert and Scott, raised close to \$45,000 for the brain tumor cause. Thank you to the family and friends of Rich, Mary, Robert and Scott!



(l to r) Jordan, Scott, Robert, Dave.



(l to r) Adam Carballeira and his son Talen celebrate Michael's memory at Ski Day.

## 4th Annual Michael Lewandowski Ski Day

On January 27, Winter Park Resort was flooded with over 130 skiers and snowboarders who turned out to celebrate Michael Lewandowski's life and raise funds to find a cure for brain tumors. A wonderful team of family and friends graciously organized this event and helped ensure it surpassed the last. Special congratulations and heartfelt thanks for raising \$20,000!

## Raising Funds, Raising Hope!

All across the country, NBTf supporters organize a wide variety of fundraising events to support the brain tumor cause. These events have ranged from a chili cook-off to wine-tasting receptions, a hand-knit scarf trunk show to stand-up comedy at a local club, and horseshoe tournaments to golf outings. Our imagination is our only limit! If you are interested in organizing a fundraising event to support the brain tumor cause, please contact **Carolyn Anderson**, Development Associate at [anderson@braintumor.org](mailto:anderson@braintumor.org) or 415.834.9970 ext. 109.

# Ask Janet



Janet, 6 1/2 years post-op

## Question: How did you tell your children about your brain tumor?

*Note: This topic generated such tremendous response that Search editors incorporated it into the cover story. Both patients and caregivers contributed to make the following a "parent to parent" column.*

When her 11-year-old daughter was diagnosed with a brain tumor, Adrienne in California says it "all happened so quickly that we really didn't have time to think through what we should tell her." The same often holds true after a parent is diagnosed.

The smallest children (5 and younger) got age-appropriate explanations in which brain tumors were a "boo-boo" or a "rock" in Dad or Mom's head. Margaret in California and her youngest son named her tumor so it wasn't so scary to discuss. My support pal Mike used NBTF's Buddy Book to help his daughter understand his diagnosis. And the older the children were, the more details they were told. Here are just a few of the suggestions parents shared.

**Be open and honest.** This tip was mentioned most. One patient adds "be sensitive to what they can comprehend, depending on the age and maturity" of the child.

**Encourage questions.** Several parents agreed, let kids know it's okay to ask questions.

**Tell them what to expect.** Help your kids cope with changes, like Jay in Massachusetts who told his son "Daddy may be tired and a little cranky due to the medicine."

**Reach out.** One mom contacted her son's pediatrician for advice. Gail in Kansas called her local Children's Hospital about counseling for kids. Michelle in Florida got guidance from Hope Hospice and says her children's church youth groups were especially supportive. Several parents talked to their children's teachers and schools about the diagnosis. Vicki in California believed the teachers "needed to understand the changes in grades, personalities and homework not getting finished" due to emergencies and doctor appointments.

**Show your positive attitude.** As one patient put it, "this was an opportunity to show my children an example of how to handle adversity."

For resources on this topic, please see the cover story.

This column reflects patient and caregiver experiences and opinions which are not a substitute for the advice of a licensed health professional.

### Next time in Ask Janet:

More comments from parents. Call 800.934.2873 or email your suggestions to Ask Janet at [nbtf@braintumor.org](mailto:nbtf@braintumor.org).

## NBTF Patient Services Receive Rave Reviews

Patients and their loved ones call 1.800.934.CURE to get answers about brain tumors and get connected with the services offered by the National Brain Tumor Foundation. The toll-free Patient Information Line is answered by Patient Services staff, who provide referrals and respond to questions about issues ranging from treatment options to local support groups, coping strategies and more.

Recently, we asked our callers for feedback about our Patient Information Line. We surveyed a representative sample of 75 callers about the services they received and how NBTF can better meet their needs. Here is what they said.

"I called because my daughter was just diagnosed and I wanted as much information as possible," one woman explained. Others called looking for support. "I was wondering what resources are available to help," said a recently diagnosed patient. Of all the callers, one-third had been diagnosed with a brain tumor, and one-half had a loved one with a tumor.

Callers received a number of services via the hotline. Thirty-five percent were referred to support-related resources, like the NBTF Support Network where patients and families can exchange experiences with others who have faced a similar situation. In addition, over 80 percent were mailed educational materials, such as *The Essential Guide to Brain Tumors* and *Coping with Your Loved One's Brain Tumor*. "The materials helped us communicate better with the doctors," one caregiver remarked.

Almost 40 percent of callers spoke with the NBTF Medical Information Nurse to help answer questions about their treatment plans. "Absolutely phenomenal!" exclaimed one caregiver. "The nurse was so kind and gave me so much information."

When asked about unmet needs, callers asked for greater attention to the financial impact of a brain tumor. NBTF helped to raise awareness about this issue through our monograph "No One Can Afford a Brain Tumor." NBTF is also expanding the Patient Help Fund to provide practical support to even more families. For details, see page 10.

Virtually all respondents said they would recommend the Patient Information Line to others. One commented, "I have told many people how responsive you are."

This survey will allow us to continue fine-tuning our Patient Information Line so we can better serve callers. Our thanks to everyone who participated. To learn more about NBTF services, call the Patient Information Line at 800.934.CURE or visit [www.braintumor.org](http://www.braintumor.org).

## No One Can Afford a Brain Tumor: NBTF Financial Survey Results

By Harriet Patterson, MPH

A brain tumor diagnosis is not only a medical crisis but a financial crisis as well, according to a new report released by the National Brain Tumor Foundation in May 2007. The report entitled, *Nobody can afford a brain tumor: The financial impact of a brain tumor diagnosis on patients and families*, was based on a study conducted by the National Brain Tumor Foundation last fall. Over 500 patients and caregiver responded to the online survey. The survey included questions about health insurance, employment changes, tumor type, time since diagnosis, income changes, out-of-pocket expenses, debt, and feelings of financial burden. Below are some key findings from the report.

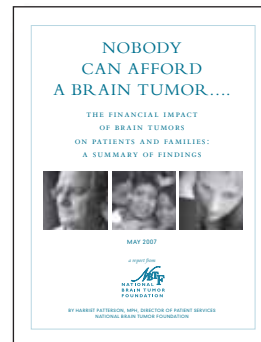
Ninety-five percent of patient respondents were working full-time when they were diagnosed, yet fewer than 35 percent returned to work full-time after their diagnosis. Caregiver work patterns were also affected, with many having to take leave, use up vacation, or quit work to care for their loved one. These employ-

**Nobody asks if you can afford a brain tumor, you just go where you are led, then your whole world just implodes on itself, and nothing is ever the same.**

— *brain tumor patient*

ment changes caused drastic drops in household income. Families earning less than \$15,000 per year went from 4.8 percent before diagnosis to 17 percent after diagnosis, more than tripling.

Nearly all (91 percent) of survey respondents had health insurance; despite this, families were struggling to pay for exorbitant COBRA premiums or fighting pre-existing condition clauses to ensure the coverage of services. High co-pays for medications were a serious concern for respondents, representing the number one out-of-pocket cost reported in the survey, with many insured pa-



tients describing medication co-pays in excess of \$1000 per month.

Disability coverage was another issue for families. Despite having paid into the system, many patients had been turned down for disability coverage because their brain tumor was not considered "disabling enough." Two-thirds of survey respondents were not receiving disability in spite of having stopped working as a result of

the tumor. Labor-intensive applications were challenging for brain tumor patients and overwhelmed caregivers, and many had their applications denied. For those receiving disability coverage, the low payments were not sufficient to make up for lost income and many families were struggling to make ends meet.

Patients and families made adjustments to their lifestyles to cover the unexpected costs of brain tumor treatment. Respondents described charging medical bills on credit cards, cashing in retirement savings, taking second or third mortgages on a home, cashing in a life insurance policy, selling homes or cars, and taking loans from family and friends. All of these had implications not only for the treatment period but for years afterwards.

In response to this survey data, the National Brain Tumor Foundation launched the Patient Help Fund nationwide this May. This program provides financial assistance grants for treatment-related expenses to brain tumor patients. Applicants must demonstrate financial need, be over 18, have a primary or metastatic brain tumor, and be residing in the United States. For more information or to apply, visit [www.braintumor.org](http://www.braintumor.org) or call 800.934.2873.

Special thanks to all patients and families who participated in this survey.

To receive a copy of the report, visit [www.braintumor.org](http://www.braintumor.org), email [nbtf@braintumor.org](mailto:nbtf@braintumor.org) or call 800.934.2873.

### NBTF Family Caregiver Program

Are you caring for someone with a brain tumor? NBTF can help. Join us for our upcoming Caregiver Training Workshops. Trainings are free; pre-registration is required.

June 15, 2007

St. Paul, MN • United Hospital

October 4, 2007

Morgantown, WV • Mary Babb Randolph Cancer Center

October 10, 2007

Charlottesville, VA • University of Virginia

October 27, 2007

Baltimore, MD • Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

# survivor's story

## Everyone Pulled Together for our Family

By Valerie Whitehill

**W**e had always taken our three children to cut down our own Christmas tree, but in December 2003, my husband Steve had been feeling badly for a while, so he took them to Home Depot to pick up a tree instead. Suddenly he started screaming in pain, and our oldest daughter, just a teenager, had to drive him home. We took him to the emergency room immediately. Steve had been having headaches since August, and his doctor kept telling him that they were caused by stress and allergies. No one realized he'd been having mini seizures.

Once he got to the hospital the doctors quickly discovered something was very wrong. Steve had surgery within a couple of days; he had a GBM stage four, in the right frontal lobe. Within 36 hours he had to have a second craniotomy. We didn't think he was going to survive. He was in and out of the hospital and rehab for two months with complications.

Then, only a few weeks later, on December 30th, I was diagnosed with breast cancer. By the time Steve came home in February, I'd already had a biopsy, lumpectomy, mastectomy and reconstruction. Our son Matthew was in eighth grade, our daughter Christine was in ninth grade, and our daughter Victoria was in eleventh grade. It was Christmas time, it was finals time, and I was spending all my time with my husband in the hospital, or getting treatment myself. I can't even remember how I told the kids about their dad's diagnosis. It was a rough time.

My family survived because of all the help we received from our community for the first six months. We were so lucky to have friends who loved us so much, who allowed me to spend my time taking care of my husband. Two of my friends took over our lives. One covered our children's needs, and the other took over our small landscape construction company. But a lot of other people also got involved in taking care of our family. I didn't have the strength to call anybody, so friends maintained two websites about our conditions so people would know what was going on. Another friend was in charge of our grocery shopping, and somebody else made sure the kids had Christmas. Friends signed up to bring us all the meals we needed for four straight months. People took our children

**The wonderful things that happened to us would not be believed.**



courtesy Valerie Whitehill

(l-r) Valerie, Victoria, Matthew, Steve and Christine on the field at a San Francisco Giants game.

to all their sports and other activities so things could be as normal for them as possible. And even two of our customers donated money so that our kids' former nanny could come spend time with us and help out every evening.

My friends immediately told the kids' schools what was going on, and that was so important, because I couldn't have done it myself right then. The schools were desperate to help. They waived the kids' finals because they couldn't concentrate right after their dad's diagnosis. My younger daughter had very understanding teachers who would adapt assignments for her if they were too upsetting, and she was allowed to go to the counselor's office if she needed time away from class. My son attended a cancer support group that his school offered—I hadn't even known about it. My other daughter received a scholarship so she could stay at her school.

My kids are very compassionate because of their experiences. One daughter is very devoted to Special Olympics and is planning a walkathon to raise money; the other volunteers for a mentoring program for inner-city girls. My son started a cancer care club at the high school with some other kids whose parents have cancer, and they are raising money and doing volunteer work.

My kids have learned to push through no matter what happens. An experience like this makes you unbelievably strong. You realize that no matter what happens and what comes along, you'll adapt and deal with it. Material objects are not as important to them, because what's really important to them is being a family and spending as much time with their father as possible. We've all learned to laugh a lot more and not take things quite as seriously. The only thing you can count on is that things change.

I would just love to write a book someday to celebrate what our community did, because what happened to us—the wonderful things that happened to us—would not be believed. If nothing else, it taught me that you can find light in life's darkest times.

## SAVE THE DATE!

### Caregiver Program Dates

June 15, 2007 • St. Paul, MN

October 4, 2007 • Morgantown, WV

October 10, 2007 • Charlottesville, VA

October 27, 2007 • Baltimore, MD

### Angel Adventure® Fundraising Walk and Community Day

Denver, CO  
June 9

San Diego, CA  
September 29

Portland, OR  
September 8

Washington, DC  
October 6

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*The information in this newsletter is subject to change. The reader is advised that information obtained from a physician should be considered more up-to-date and accurate than the information in the newsletter and that this newsletter does not and cannot purport to address facts and circumstances particular to any patient. This is something that can only be done by the patient's physician. Sponsorship of this newsletter does not imply the National Brain Tumor Foundation's endorsement or recommendation of any particular form or forms of therapy, regimen or behavior.*

SEARCH is published by the National Brain Tumor Foundation, a non-profit organization that raises funds for research and provides support services to patients, their families and friends.

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Tumors  
Getting a Second Opinion

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